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# Exploring the Experiences of Women and Health Care Workers in the Context of PMTCT Option B Plus in Malawi

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**Introduction:** Malawi has embarked on a “test-and-treat” approach to prevent mother-to-child transmission (PMTCT) of HIV, known as “Option B+,” offering all HIV-infected pregnant and breastfeeding women lifelong antiretroviral therapy (ART) regardless of CD4 count or clinical stage. A cross-sectional qualitative study was conducted to explore early experiences surrounding “Option B+” for patients and health care workers (HCWs) in Malawi.

**Methods:** Study participants were purposively selected across 6 health facilities in 3 regional health zones in Malawi. Semi-structured interviews were conducted with women enrolled in “Option B+” (n = 24), and focus group discussions were conducted with HCWs providing Option B+ services (n = 6 groups of 8 HCWs). Data were analyzed using a qualitative thematic coding framework.

**Results:** Patients and HCWs identified the lack of male involvement as a barrier to retention in care and expressed concerns at the rapidity of the test-and-treat process, which makes it difficult for patients to “digest” a positive diagnosis before starting ART. Fear

regarding the breach of privacy and confidentiality were also identified as contributing to loss to follow-up of women initiated under the Option B+. Disclosure remains a difficult process within families and couples. Lifelong ART was also perceived as an opportunity to plan future pregnancies.

**Conclusions:** As “Option B+” continues to be rolled out, novel interventions to support and retain women into care must be implemented. These include providing space, time, and support to accept a diagnosis before starting ART, engaging partners and families, and addressing the need for peer support and confidentiality.

**Key Words:** HIV, PMTCT, ART, test-and-treat, retention, uptake, loss to follow-up, Option B+, Malawi

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## INTRODUCTION

In Malawi, a country of 15.9 million people in Southern Africa, an estimated 10.3% (9.6%–10.8%) of adults are HIV positive, and an estimated 170,000 children younger than 15 years are living with HIV, most of whom were infected through vertical transmission.<sup>1</sup> Since July 2011, the Malawi Ministry of Health has embarked on a program to prevent mother-to-child transmission (PMTCT) of HIV known as “Option B Plus” (Option B+). Malawi became the first country to implement a test-and-treat approach in a national PMTCT program: Option B+ offers all HIV-infected pregnant and breastfeeding women lifelong antiretroviral therapy (ART), regardless of CD4 count or clinical stage.<sup>2,3</sup> The overall goal of the program was to improve ART uptake and retention, and thus the outcomes of HIV-infected pregnant women, their uninfected partners, and their infants within the continuum of HIV testing and treatment services.

The Option B+ strategy offers an attractive rapid ART scale-up and was adopted in Malawi ahead of the recommendations from the World Health Organization.<sup>4</sup> Although it has the potential to profoundly impact maternal and infant outcomes, operational challenges throughout the cascade of PMTCT services may affect uptake and adherence to ART by pregnant women, the follow-up of HIV-exposed infants, and the long-term retention of this population. From the onset, potential threats to the implementation and scale-up of Option B+ were identified and concerns were raised in relation to initiation into care, retention in care, adherence to ART, and

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The PURE trial was registered with ClinicalTrials.gov (ID number NCT02005835).

PURE Malawi Consortium members are listed in Appendix 1.

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the lack of psycho-social support in the context of lifelong retention of a relatively asymptomatic population group.<sup>3</sup>

During its first year of implementation in Malawi, Option B+ rapidly expanded uptake and access to PMTCT services, with a 7-fold increase in the number of women starting ART for PMTCT.<sup>5,6</sup> One of the main challenges encountered to date is the retention of women once initiated on ART. In the first year of implementation, a large proportion of women (17%) seemed to be “lost to follow-up” (LTFU) 6 months after ART initiation, with most losses occurring in the first 3 months of therapy.<sup>7</sup> Many women recorded as initiated on treatment and who accepted their first month of ART never come back, raising additional questions on whether they initiated treatment. Early assessments into the reasons associated with stopping ART among women who initiated treatment during Option B+ pointed at difficulties linked to traveling to health facilities and lack of transport money, not understanding initial treatment guidance, and being too weak, sick, or experiencing treatment side effects.<sup>8</sup>

In light of these potential challenges to the implementation of Option B+ in Malawi, a cluster randomized control trial, PURE (PMTCT Uptake and Retention in Malawi), was designed to evaluate and compare strategies to strengthen uptake and retention of mothers and families in PMTCT care. The trial compares facility-based peer support and community-based peer support to standard of care across the South East, South West, and Central West regions.<sup>9</sup> Interventions include the introduction of trained expert patients (Mentor Mothers and Expert Mothers), who are working within and outside health facilities to support women involved in Option B+ and their families. In this article, we describe the results from a qualitative formative study designed to refine the PURE trial intervention arms. The aim of this study was to explore the experience of patients and health care workers (HCWs) in relation to the implementation of Option B+. The specific objectives were to elicit local perceptions of Option B+ among HCWs and women who have recently been enrolled in this program and to document the nature of the support provided to these women.

## METHODS

### Study Design

This was descriptive, cross-sectional formative research, drawing on a qualitative approach to collect data through semi-structured interviews and focus group discussions with both Option B+ patients and HCWs.

### Study Sites

The study was conducted in 6 of 21 facilities within the PURE trial sites across 3 health zones (Central West, South East, and South West).<sup>9</sup> Among the 21 study sites included in the PURE trial, 2 sites were purposively selected for this analysis in each health zone. In addition, in each health zone, we selected 2 sites that were different according to their location (rural vs urban settings), number of pregnant and/or breastfeeding women attending services in the past quarter

(large vs smaller facilities), and type of ownership of the health facility (Ministry of Health vs Christian Health Association Malawi). The health facilities identified as study sites for the study are shown in Figure 1.

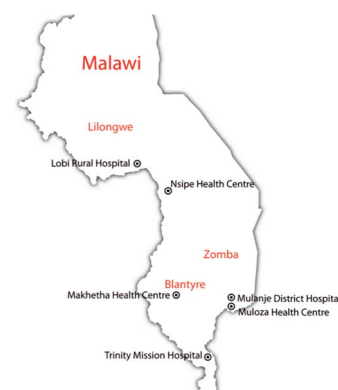
### Participant Selection

Study participants were recruited through a purposive sampling approach at each study site until the sample of respondents was achieved. In each site, the research team identified 4 women newly initiating ART services and enrolled in Option B+, and all available HCWs involved in providing services as part of Option B+. Our intention was to interview a small sample of individuals until thematic saturation is achieved. Based on previous studies conducted in the same setting in relation to PMTCT services, we expected that saturation would be achieved at 20–30 interviews; we therefore selected 24 interviews (4 per site) as a suitable number of women to be interviewed.

HCWs recruited for the study included nurses, medical assistants, and community health workers (Health Surveillance Assistants) who routinely provided PMTCT care in the selected health facilities. Patients involved in the study included HIV-infected pregnant or breastfeeding women seeking antenatal care (ANC) or initiating ART services at 1 of the 6 study sites. In total, 48 HCWs and 24 women receiving care as part of Option B+ were included in this study.

### Data Collection

All data were collected at the health facilities at a time identified as convenient by research participants themselves. Data collection methods included semi-structured interviews and focus group discussions. Semi-structured interviews were conducted with 4 patients in each study site ( $n = 24$ ). One focus group discussion was conducted with 8 HCWs per facility ( $n = 6$  groups of 8 individuals). Data collection took



**FIGURE 1.** Geographic distribution of the 6 PURE formative sites in the South East, South West, and Central West zones of the country (Mulanje District Hospital and Muloza Health Centre in the South East zone; Trinity Mission Hospital and Makhetha Health Centre in the South West zone; and Nsipe Health Centre and Lobi Rural Hospital in the Central East/Central West zone).

place from April to June 2013. (A follow-up longitudinal study is collecting additional data alongside the PURE trial implementation from 2014 to 2016). A team of 4 data collectors was recruited and trained in recruitment of study participants, data collection, and appropriate conduct during fieldwork, including ethical considerations. All data collectors had previous experience in collecting qualitative data and conducting interviews and received additional training specific to this study. Data were recorded on digital audio recorder in the local language Chichewa.

## Data Analysis

Recordings of interviews and focus group discussions were transcribed in Chichewa and later translated verbatim to English. The quality of the transcription was checked by a bilingual researcher who used the original transcripts and extracts from the audio files to check the final translation. Data were anonymized and pseudonyms were used to protect the identity of research participants. Based on a sample of 10 transcripts from interviews and focus groups, the research team identified themes primarily through a deductive approach.<sup>10,11</sup> Using a framework analysis<sup>12</sup> approach, themes were developed to capture common issues, such as perception and acceptability of current care, adherence and loss to follow-up, care relationships, disclosure, and task-shifting involving community HCWs. A coding structure reflecting each of the themes and subthemes was applied to the data using *Nvivo* 7. Framework and thematic analysis of the retrieved data were followed by a narrative account of the findings.

## Ethical Considerations

Data were collected with respect for international ethical guidelines, aiming at protecting confidentiality and anonymity, ensuring informed consent, giving ample time and information about the study to respondents, and interviewing study participants in location allowing for audio privacy. All study participants provided written informed consent. Study participants did not receive an incentive to be part of the study but they received a transport reimbursement (equivalent USD 1.40) for taking part in the interviews and focus group discussions. The study protocol was approved by the National Health Sciences Research Committee in Malawi, the University of North Carolina Institutional Review Board, The University of Toronto Research Ethics Board, and the World Health Organization Ethics Review Committee.

## RESULTS

Women interviewed were between 19 and 40 years old (mean age: 28 years). All but 2 were married (one was not married and the other was divorced), and all but 3 had 1 child (3 were pregnant). Most had reached junior primary school, and 8 of 24 had completed the first or second years of senior primary school. For those who had an economic activity, this ranged from farming (6 of 24), small business (7 of 24), and small labor or seasonal work in tea plantations (4 of 24).

Results are presented across 3 main themes: the perception of Option B+ by patients and HCWs; experiences of adherence and loss to follow-up in the context of Option B+; and patients' and HCWs' perspectives on improving Option B+.

## Perception of Option B+ by Patients and HCWs

Several of the women interviewed were tested for HIV during pregnancy and talked about how they accepted their diagnoses and sought treatment. Some respondents also narrated their desire to have more children in the future, which was sometimes linked to the perspective of getting better on ART.

Distance, privacy, and confidentiality remain problematic issues for women, especially for those living in rural areas; they expressed feeling stigmatized in relation to living with HIV, within their social network and during their visits to the health centers. In most cases, women were reluctant to share their serostatus beyond a small circle of people because they feared discrimination. Several of the women interviewed had not disclosed their serostatus to more than one person:

No one knows because I have never explained this to anyone as it is only me and my husband that know about this. [Nsipe] I have just told my husband, but I have not told my children since they are with my mother. [Makhetha]

Across several health centers, women criticized the lack of privacy in HIV and ART services, with confidentiality around their serostatus compromised each time they go to the clinic:

If you meet a person who knows you and is seeing you enter the room where we get ARVs [antiretrovirals], they tend to tell people that so and so are on ARVs. [Lobi]

In each health facility, the women interviewed expressed how much stigma is still part of their lives and that they still face discrimination when they choose to disclose their serostatus to others:

Disclosure of HIV in my community is difficult because when people know that you are HIV positive, they start telling each other about your status. So wherever you go, people talk about you. As such, I am open only to my family and close friends. [Trinity]

Some of their close family members avoided coming to their houses and, in 2 cases, the husbands decided to leave after their partner tested positive:

Since I was found HIV positive [...] my husband ran away from me. I have to support the child alone. [Nsipe]

The lack of inclusion of male partners, and their reluctance to be tested for HIV, was cited as an ongoing

problem by women; some feared for the stability of their relationship if their partner did not test. Many of the mothers who expressed being supported by their partner to get an HIV test and start treatment also reported that male partners refused to get tested or to start ART themselves:

My husband is refusing to go for testing, therefore I don't know if my family will continue to live in this situation. [...] will the marriage come to an end? [Muloza]. My husband supports me but he doesn't take the drugs. [Nsipe]

From the HCWs' perspective, Option B+ was positively received as it encouraged deliveries at health facilities to get babies on nevirapine within 72 hours. They also expressed positive views about the intensified testing of newborns and that Option B+ would encourage continuous breastfeeding until 24 months.

Across all sites, HCWs complained about the lack of infrastructure and the recurrent shortage of HIV test kits. Some HCWs expressed challenges to identify the address and exact name of patients for follow-up.

Importantly, HCWs reported that some mothers experience difficulties in understanding why they are initiated on ART immediately after testing. HCWs were concerned that the "test-and-treat" approach is "too fast" and too much information is given to women at once, with no time to digest and communicate a new positive HIV diagnosis:

We test her [a patient] today and she is found HIV positive, we immediately initiate her onto ART whilst she is still thinking about how she contracted the virus and she hasn't yet accepted the reality about her serostatus, and we give her the drugs for her unborn child at the same time. So it's like she is getting too much information at once before she makes the rightful decision [Mulanje].

Another challenge experienced by HCWs is that, because of staff shortages, some mothers are asked to come back another day to be tested. Similarly to patients, HCWs highlighted the lack of privacy and confidentiality when patients came for testing or to pick up ART:

The space where VCT [voluntary counseling and testing] and ART clinics are conducted is small, so on ART day the space is overcrowded. Therefore privacy is compromised. [Nsipe]

### Adherence and Loss to Follow-up in Option B+

Most women interviewed self-reported that they were adhering to treatment by taking ART as prescribed and understood that they should take treatment for life:

They explained to me that I would be taking these drugs daily for the rest of my life. [Nsipe]

Despite declaring that they adhered to treatment, and generally understanding well how to take ART, nearly all

mothers and HCWs interviewed reported problems linked to retention in care and adherence to ART; some patients reported missing doses of ART while they continued to collect treatment regularly from the clinic.

HCWs reported that several mothers did not come back after delivery or after their first visit to the health facility. HCWs expressed that patients feel "discouraged" when they see people they know queuing for ART. HCWs reported that the LTFU may be explained by the fact that women are expected to start treatment immediately, sometimes while they are still in the labor ward:

Once we diagnose them [patients] positive, we immediately initiate them on ART. So you find that most of them don't come for subsequent visits because they were introduced to ARVs while in pain. This is a common problem and most of the defaulters belong to this category of ladies initiated at labour ward. [Trinity]

A key concern expressed by HCWs was that they do not always know how to follow-up with the mothers who may be defaulting. Some HCWs noted that the loss to follow-up was also because of the lack of involvement of male partners in PMTCT care, for instance, because men did not accompany women to ANC or because they were not routinely tested for HIV and followed-up within PMTCT services:

Because men don't accompany their spouses to antenatal clinic, it happens that once the lady delivers and she is not suffering from any disease, she does not see the reasons for coming to the clinic to continue ART treatment. This is because men are not involved. [Trinity]

### Perspectives on Improving Option B+

When asked how one can improve the current PMTCT care in Malawi, the main suggestion from women and HCWs was to encourage more men to come forward for HIV testing and to start treatment when required, for example, by improving couple counseling and testing initiatives. Many patients would have liked additional "life skills" advice (for example, skills to be empowered to improve their day-to-day situation) to be included in the care package that they received at health facilities. Family planning and contraception as well as nutrition and income-generating activities were cited as important aspects of PMTCT services to be considered. Another suggestion from patients to improve PMTCT care was to address the issues around privacy and confidentiality. Some suggested having a specific day for ART visits to get drugs "as a group":

[In order to improve confidentiality] we should have a special day for ART visits to get drugs as a group. [Nsipe]

From the HCWs' perspective, more training was necessary to help patients enrolled in Option B+. Distance, especially among rural health facilities, was an obstacle to

trace patients LTFU. HCWs suggested that task sharing with Health Surveillance Assistants (HSAs) was important to link patients back to care and that bikes and motorbikes could help them to address this issue:

We have many clients who come from far and we do not know if their reason for defaulting might be that they are dead or not, so if we can have another motorbike and make the effective follow-ups we can have a successful ART. [Lobi]

## DISCUSSION

This study explored the experiences of women and HCWs in the context of the early rollout of Option B+ in Malawi. Our findings illustrate that patients and HCWs identified the lack of male involvement as a barrier to retention in care and expressed concerns at the rapidity of the test-and-treat process. Fear regarding the breach of privacy and confidentiality were also identified as contributing to loss to follow-up of women initiated under the Option B+ strategy. Similar to recent studies exploring the challenges to implementing Option B+ in Malawi, we note that stopping treatment within the first few months of ART initiation may be linked to lack of means of travel and transport money, not understanding how to take ART, informal transfers between health facilities, or being too weak/sick and drugs side effects.<sup>8</sup>

In addition to health systems barriers, such as the irregular availability of CPT and HIV test kits, and the lack of infrastructure and human resources for health, our findings illustrate that stigma, confidentiality, and privacy remain central concerns for women accessing PMTCT services in the context of Option B+. As described by others,<sup>13–16</sup> despite the broader availability of ART, women continue to fear stigma in relation to being publicly identified as living with HIV.

To understand the experience of receiving care and support under Option B+, it is crucial to consider the different cadres of HCWs involved in providing PMTCT care; HSAs, in particular, have an important role to play, especially outside health facilities. HSAs perform a number of tasks within the PMTCT cascade, often without receiving additional specialized training, for example, to carry out tracing activities. HSAs are required to spend a considerable portion of their time in health facilities to assist HCWs; as their roles and responsibilities continue to expand in the context of Option B+, it is important for their roles to be rationalized to ensure that they are not overwhelmed by the large number of tasks that are shifted to them.

Some of the key reasons identified by HCWs as contributing to early loss to follow-up include lack of support from family members, fear for breach of confidentiality, feeling discouraged at the prospect of lifelong ART, and lack of partner involvement. Male partner involvement is viewed as a key intervention by patients and HCWs and remains inadequately addressed in current PMTCT interventions. However, as others<sup>17</sup> have noted, male partner involvement in PMTCT care is fragmented and, at best, associated with

first ANC and couple HIV counseling and testing, suggesting poor integration of male involvement into existing programs.

Similar to a study from Nigeria,<sup>18</sup> our results indicate that nondisclosure is a factor that may contribute to non-retention in Option B+. Disclosure remains a limited and difficult process within families and more particularly within couples. In addition, our data support the results described in other studies that explored couple testing and disclosure<sup>13,19–24</sup>; although male involvement is associated with better early retention on ART, a majority of pregnant women living with HIV face difficulties in sharing their serostatus with their partners and fear being rejected by their partners.

Importantly, patients and HCWs were concerned about the rapidity of the process for same day test-and-treat. Our study highlights key concerns regarding the immediate nature of this approach, where patients are given little time to “digest” a new diagnosis and start treatment. This was highlighted by patients and HCWs as a crucial concern regarding the implementation of Option B+. Our results confirm that some women may find PMTCT intervention coercive<sup>7,13</sup> or that they are not adequately prepared to start ART.<sup>7</sup> In addition, in rural Malawi, HIV testing may, in some cases, be incompatible with marriage because it may be perceived as against ideals of trust, love, and intimacy that couples strive for in their relationships.<sup>25</sup> Hence, the use of same-day HIV testing and ART initiation may be contributing to the inadequate uptake of treatment under Option B+, which points to the need to identify alternatives or enhancements to this approach for women who are unable to start treatment right away—for instance, enhancing support for women after testing, tracing male partners early, improve couple testing procedures, and help women overcome the hurdle of disclosure.<sup>24,26</sup>

## Limitations of the Study

Although study sites were carefully selected in relation to criteria described in the methods section, the purposive selection of patients and HCWs at each site may not reflect some of the challenges of the current implementation of Option B+. In addition, this study focused on patients currently retained in care, who may have a different perspective on Option B+ services to that of patients who have been LTFU.

## CONCLUSIONS

As Option B+ continues to be rolled out across Malawi and in several other sub-Saharan African countries, new interventions to support women to be retained into care must be implemented. Novel types of interventions, for instance, providing care through other mothers who are also enrolled in Option B+, are seen by some patients and HCWs as providing more personal and family-centered peer-supported care, but key questions remain as to how these interventions will cope with patients' perception of the quality of care received and with expectations placed on peer support mothers. Current Option B+ interventions should consider the lack of patient agency during treatment initiation in relation to early loss to follow-up; Interventions should improve processes to providing appropriate space, time, and support for patients to

accept a positive HIV diagnosis before starting treatment, engaging male partners and families into PMTCT care, and addressing the need for peer support and confidentiality expressed by women who are already accessing PMTCT care.

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## APPENDIX 1. PURE Malawi Consortium

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